Introduction

Equitable distribution of health care resources requires accurate morbidity and mortality data for all racial and ethnic subgroups of the population. Medical records or other non-primary sources of racial or ethnic identification may be prone to higher errors than information collected directly from the individual. Many studies have shown that for American Indians and Alaska Natives in particular, there is a large amount of misclassification on death certificates and in other disease surveillance systems. Several studies compared death certificates to Census data, Indian Health Service (IHS) records, or tribal registries to assess accuracy of mortality statistics.[1–6] A few compared death certificates to disease-specific registries where race and ethnicity were reported directly from the patient to assess accuracy of disease incidence statistics.[7–12] Some studies used national data,[1,4] while others used state or regional data.[2,3,6–11] One study compared Veterans Affairs self-reported race to an administrative database.[13] All these studies found varying rates of misclassification of American Indians as non-American Indian, with misclassification rates varying from a low of 9 percent to a high of 96 percent. Misclassification increased as the percentage of American Indian "blood quantum" decreased.[2,6,8]

Evidence of misclassification has been documented in North Carolina as well. The North Carolina Central Cancer Registry (CCR) submitted its 1995–2005 incidence data to the IHS and 21 percent of those identified as American Indian by the IHS were identified as a different race in the cancer incidence records. Similarly, a linkage between North Carolina death certificates and the IHS data suggested a 17 percent underreporting of American Indian race on North Carolina death certificates.[6] This pervasive misclassification of American Indians may result in substantially underestimated mortality and morbidity rates for American Indians in North Carolina.

The studies cited above mostly relied on IHS data to estimate misclassification rates of mortality and morbidity. These data include patient records for federally recognized American Indian tribes covered by the IHS, which cannot necessarily be generalized to regions such as the southeastern United States, where the majority of the American Indians are not federally recognized and not served by the IHS. North Carolina has the largest population of state-recognized, non-federally recognized American Indians in the United States.[14]

The objective of this study is to evaluate the accuracy of classification of American Indians in North Carolina's cancer incidence records, and to estimate the effect on reported cancer incidence in North Carolina, where the majority of American Indians are not associated with federally recognized tribes.

Methods

Data Sources

We estimated misclassification rates of race in the CCR for American Indians in North Carolina. We matched cancer cases from the CCR to tribal rolls for seven non-reservation Indian tribes in North Carolina: Coharie, Haliwa-Saponi, Lumbee, Meherrin, Occaneechi Band of Saponi Nation, Sappony, and Waccamaw-Siouan. To test if American Indian cancer records in the CCR are correctly classified as American Indian, all cancer records for the main counties in which each tribe resides were matched to the tribal rolls. For those records that did match to the tribal rolls, we determined if the race was classified as American Indian in the CCR. This project was developed through a partnership between the CCR, the Carolina Mammography Registry (CMR), and the North Carolina Commission of Indian Affairs (NCCIA) with assistance from health outreach coordinators and tribal enrollment officers who were critical to the collection of data.

IRB Approval

Approval was obtained from the North Carolina Division of Public Health Institutional Review Board (IRB) as well as the University of North Carolina School of Medicine IRB. All personnel were trained on Health Insurance Portability and Accountability Act (HIPAA) rules and rules of confidentiality.